Int J Disabil Hum Dev 2009;8(1):67-73.
Running title: The family care giver

The family caregivers journey in end of life care: Recognising and identifying with the role of carer

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Abstract: The process of dying in the 21st Century is often protracted. An ageing population and increasing long term conditions have resulted in a need for increased palliative and end of life care. Formal health care services are unable to fully provide the level of support required at the end of life. Increasingly therefore family caregivers are being relied upon to provide often complex interactions and support to people who are dying. More is now understood about the activities they engage in and their potential support needs, however, the carer role is an elusive concept that many carers in palliative and end of life care settings do not recognise or identify with. This has implications for the interactions they may share with health and social care professionals. Drawing on current literature, policy, and a qualitative study of the perceptions of family caregivers in a palliative care setting this paper will seek to consider the role of family caregivers in palliative care settings and to explore the ways in which health and social care practitioners can assist them in undertaking this role.

Keywords*:* Family caregivers, palliative care, end of life care, terminal care, role

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Submitted: September 29, 2007. ***Revised:*** June 28, 2008. ***Accepted:*** July 04, 2008.

INTRODUCTION

Dying in the early 20th Century was characteristically sudden and usually as a result of acute infection, birth, accident or trauma (1). Dying in the 21st Century in western society is different. Increased life expectancy has resulted in an ageing population (2). However, this does not mean that people are living longer in a healthy state. Rather, there is evidence that the last few years of an extended life may be spent with more chronic illness and disability (3-5), which will require additional and increasingly complex help and support from others. Dying has therefore become a protracted process often requiring specialist support. As a consequence caring for the dying has moved from a short term commitment to an extended course of action.

As individuals live for longer periods with chronic illness there are increasing difficulties for policy makers and service providers, as limited finances and resources result in a shortfall of available formal support. Informal networks of family and friends are increasingly relied on to fill the gap between formal support and actual need for individuals who are dying or at the end of life (6-9). In addition, these informal networks are often required to provide complex and skilled support to the ill person (10,11), which may result in pressure on individual carers (12).

The purpose of this paper is to consider the development of the role of "carer" and the support needs of the family caregiver in palliative and end of life settings. Drawing on current

literature, policy, and a study of the perceptions of family caregivers in a palliative care setting, an exploration of the potential impact on the development and delivery of health and social care services will be considered.

BACKGROUND

Caring at the end of life

Motivation to care at the end of life may be the result of the relationship to the ill person, societal expectations and previous experience (13). Typically, people become involved in caring as a result of their kinship or relationship with the ill person. Often there is little preparation for this role or any degree of understanding of the consequences and implications for the individual carer (14,15). At first caring may be viewed as a short term commitment, relatively easily engaged in and combined with other activities of living. However, as time progresses the ability to engage in caring activities may be more difficult to maintain (16).

Within palliative and end of life settings there is an implicit assumption, particularly if the ill person is diagnosed with cancer, that the time span for caring will be short. However, the perceived short time frame does not necessarily reflect the reality of the situation. With early diagnosis and new treatment regimes 60% of cancer patients may survive at least five years (17). Thus, becoming a carer for someone at the end of life may become a protracted role and involve supporting the ill person through periods of active treatment, remission, recurrence, and gradual or fast deterioration prior to death (18).

Defining family caregivers

So who then is considered to be a family caregiver in palliative and end of life care settings? The concept of family can be defined in a number of ways, and may represent members of a nuclear family or individuals with non-blood bonds (19). Family caregivers will generally be providing care in an unpaid capacity, although in some countries may be in receipt of financial benefits. They may or may not have formal training and qualifications in caring in general, although many will develop high levels of expertise in caring for the ill person. Within this paper family caregivers or carers will be the person or persons who have primary responsibility for the day to day care of the person with incurable disease or who is nearing the end of life. Very often within palliative and end of life care one person, usually co-resident with the ill person, takes the predominant caregiving role and is supported in this by more extended family and friend networks (16,18,19).

Palliative care

The World Health Organisation (20) defines palliative care as is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness. Thus, palliative care has always had a strong emphasis on supporting family members (21), and views the family as a unit of care (19). In fact carers are considered to be holding the unique position of both giving and needing support (22), and it has been suggested that it is not always clear who is the ‘patient’ (23). This may create problems for the health professional when there is a conflict of interests between the family and the person being cared for.

Despite the WHO (20) recognition of the importance of palliative care for all individuals facing a life threatening illness, access to service support is not always equitable. In the UK specialist palliative care support has largely been developed in relation to cancer patients and their families (4). Specialist services, such as those provided by a hospice or hospital palliative care team, are able to offer additional formal support to the ill person and the family caregive,r which may assist them in maintaining the caring role. Such additional support for the carer may also help to facilitate the desire of the ill person to die at home (24),

as a breakdown in the caring activity is a common reason for the admission of the dying person to hospital or hospice immediately prior to death (25-27). Conversely for those caring for individuals dying of chronic degenerative conditions access to additional specialist formal support is limited. As these long term conditions are likely to require prolonged and often increasing care needs, there will be an impact on the family caregivers' ability to maintain a caring role until the person dies (28). In addition, given the increasing population age (29), those caring for someone who is at the end of life will potentially experience multiple health problems and co-morbidity issues themselves, which may also impact on their ability to undertake a caregiving role (30).

Policy

Current social policy in the UK is aimed at supporting individuals with long term chronic conditions at home in the community (31). For those people who have supportive and palliative care needs there is great emphasis placed on facilitating the patient's preferences for death at home (32; 33), despite some indications that with a deteriorating condition home is not always the preferred place of death (33). Given the acknowledgment of the crucial role that family caregivers play in facilitating the support of patients dying in the community at home (12; 9), the question faced by health and social care professionals is 1) what are the support needs of these caregivers and 2) how can this be provided. In addition there is also a crucial question of the recognition and identification with the term carer by the family caregivers themselves. To begin to address these questions I will be drawing on a qualitative study that was conducted with carers to explore the nature of their role and sources of support over time. All names of carers have been changed to protect their anonymity.

THE STUDY

The study was based on a longitudinal case study approach. This facilitated the acknowledgment of important background and situational information to be considered as part of the data collection and analysis within the research. One of the study aims was to identify the family caregivers perception of their role over time. Sixteen family caregivers (eight husbands, six wives and two adult daughters) from two areas in the south of England were interviewed over a four month period. The age range of the family caregivers was 33-77 with a mean of 56.8 years. All were recruited through the visiting specialist palliative care services, and all were caring for someone with a cancer diagnosis with a prognosis of six months or less.

Each family caregiver was visited up to four times over a four-month period. Detailed interviews were conducted with the family caregivers alone if possible, although seven chose to be interviewed with the person they were caring for. The interviews focused on their role, relationship with visiting health professionals, and other sources of support. All interviews took place in the caregivers' own home and lasted between one and two and a half hours. Each interview was tape recorded and later fully transcribed. Each transcript was then subjected to a continuous reading and re-reading in order to elicit themes and issues that were relevant to the family caregivers.

The carers journey – how it begins

Just as the ill person can be said to experience a journey from initial diagnosis to end of life, so too can the family caregiver. From initial symptom recognition and diagnosis to the end stages of life, the family caregiver is likely to have shared the experience with the ill person (34). The carer is frequently present at consultations with the ill person and may be relied upon to ask questions that the patient does not feel able to address. Caring at the beginning of

the journey is seen in the light of previous care given or received for other ailments throughout the relationship experience. For example one husband in the study stated that:

> "*Cos when you're actually married to someone you're there through thick and thin anyway aren't you? If I was ill she'd look after me, and if she was ill I'd look after her. Um, I remember when I was in hospital, I had two bad injuries playing rugby, where I was put in hospital and I had an operation. When I came out I couldn't, I was on crutches. She always looked after me then. I mean it's just this is, I don't know, a bit longer that's all." Mr Lloyd.*

For others the care given was also linked to the relationship that they had shared for many years and the wish to continue to share in all its aspects. Mr Sawyer was caring for his wife of over 40 years and stated that his motivation for caring was this love and concern:

> *"It can apply to a husband or wife who've been married for 40-50 years and are still in love with each other as much. So the word caring would probably not apply there. Be just love and concern for the other person. That's what the motivations would be."*

As a result of the demands to care or support the ill person, the family caregiver can often ignore their own needs. Indeed it was noticeable that all the carers interviewed initially gave a history of the patient's story rather than identifying their own perspectives, despite being encouraged to discuss what it was like to be a carer. What was seen as important at this stage was to support the ill person in both practical and emotional terms. Thus, the carers undertook additional household and child care responsibilities, spent time sitting with the ill person and accompanying them to hospital appointments.

Initially some of the ill people and their carers were given a poor prognosis. This led to an imperative to undertake care immediately and to avoid missing any time together. This had immediate consequences for some of the participants, as in the case of Mrs Nash. When her mother was diagnosed as having lung cancer and a prognosis of only six months her mother asked her daughter to be with her. Mrs Nash's response was immediate and unconditional:

> *"Well, I used to work. Umm, when Mum found out about her illness, um, she said would you be there at home with me in case I need you? And I said yes."*

For Mrs Nash, there was no question that she would not be there for her mother, despite the restrictions that this action placed on her own life and that of her own family. Within palliative care one of the strong motivating factors for participating in care is the belief that there is limited time to share and be together and a desire not to waste any time and to 'get it right' for the dying person. However, for Mrs Nash and some of the other carers maintaining this level of commitment and involvement became extremely difficult when it was conducted over a longer period of time than originally anticipated. Mrs Foster questioned at times her ability to continue to maintain the level of support that her husband required.

> *"You sort of run out of momentum sometimes. ... Because you begin to wonder yourself sometimes, which is only, you know, understandable is there going to be an end."*

In this respect some of the family caregivers experienced a degree of burden that is often associated with other long term caregiving. The difference here was the unexpected nature of

this reaction due in part to the initial indications of remaining time span from the medical diagnosis and prognosis.

Development – becoming a carer

After the initial shock of diagnosis and being told that the person you care for has a terminal illness there is often a period of adjustment. The carer takes on new roles and responsibilities, which may include the obvious domestic activities or responsibilities that may have previously been the domain of the ill person, maintaining a positive outlook for the ill person and others, and for some developing new skills relating to the medical care required (35). Mr Lloyd found the changing roles and responsibilities challenging at first.

> *"I do everything around the house. Do the cleaning, cooking, looking after the kids, the washing. Just got used to it now. (laughs). ... When she was well I just used to come home like and have me dinner ready, made for me like. Big shock this."*

Other changes in the lives of the family caregivers were also noted. In particular for those carers who were employed there were issues about when and how to take time off. Sometimes the employer was particularly helpful and adjusted the carer's hours to fit in with their new responsibilities.

> *"They've (work) been really good to me since we found out. Um, I've had (a change of job) so I can get the time off to look after her. So job wise they've been really good to me."* Mr Lloyd.

For one carer, whilst work was able to allow some flexibility in working hours this was not always desired as work was viewed as 'time off' from thinking about the situation and she was therefore reluctant to give this up. This caused tension with her husband who had taken early retirement due to his illness and who wanted Mrs Foster to work part time in order for them to spend more time together.

> *"He's had to take early retirement. ... Um, in fact he's talking about me not going to work full time any more because he'd like me to be around at home."* Mrs Foster.

For other caregivers work was less sympathetic which also caused some tension.

> *"I had to have my holidays, I took some of me holidays. But um, I thought there might have been some, you know, perhaps a little bit of compassion. I didn't expect to have months off, but the word profit the word profit was mentioned."* Mr Bradley.

Undertaking these new and extended roles however did not necessarily mean that the family caregiver recognised themselves as a 'carer'. Within the study, whilst some family caregivers strongly identified with the term carer, others did not.

> *"I've been a carer all my life. I've always done something for somebody. I've never had nursing training, but it's a natural instinct, it's born in me."* Mrs Vaughan.

For Mrs Vaughan a major concern was what she would do when her need to care ended, and she commented;

> *"What do the carers do when the caring ends?"*

For other carers' there was only a recognition of a undertaking a caregiving role after considerable periods of time, and often following increasing contact with health and social care professionals. Sometimes the individual's recognition that their activities could be construed as a caring role only came following conversations with others, as in the case of Mrs Page when one of the staff at the social care day centre that her mother attended said:

"You must be your mother's carer. So I thought, well I suppose I am."

Adopting a 'carer' role may result in some family caregivers acting as the representative of the ill person (38), or becoming the co-ordinator of care between the visiting health and social care professionals and the patient (16). Whilst this is a valuable role and may facilitate good care between different service providers the ill person and the family members, it may also serve to prevent the family caregiver from acknowledging their own needs for information and support.

Such lack of recognition of the role of 'carer' may have implications for the interactions between family caregivers and health and social care professionals. If both groups have different levels of understanding of the role and activities this will involve, there may be a danger of family caregivers being unexpectedly placed within the position of accepting responsibility for the care and monitoring of the patient that might be outside their ability to manage (36,37). Understanding the role that the family caregiver themselves associate with their involvement may be important in tailoring the appropriate level and type of information and support required by the individual (38). Explicit recognition of the role would also result in an open acknowledgement of the family caregiver position, which in turn would have the benefit of highlighting the rights and needs of this group. This would help health and social care professionals to identify clear areas of responsibility and priority towards the family caregiver.

There is a need to be aware of the differences each family caregiver may bring to a situation in order to work most effectively with them, for example, in ensuring the safety and well being of both the family caregiver and the person they are caring for. This raises challenges in the development of supportive working relationships by health and social care professionals. First, if the individual does not recognise themselves to be a carer then it may influence how health and social care professionals interact and support the person. For example, a study by Armes and Addington-Hall (39) found that health and social care professionals relied on carers to assess and manage symptoms, although carers themselves did not always know what they should monitor. Second, the expectations of the involvement of the family carer may be incompatible with the carers own expectations and this will inevitably influence the level and type of support they can access (16).

In the general care giving literature there has been an acknowledgement that family caregivers acquire experience and expertise over time, resulting in the development of an alternative typology which views informal carers as 'experts' in caring (40,41). Within this framework the family caregivers' expertise may be supplemented or enhanced by professional carers. Services in this scenario work with the family caregiver to provide optimum care and support to the cared for person, whilst acknowledging the developing expertise that these individuals acquire. For the caregivers in the study the development of this level of expertise was facilitated by their interaction with the specialist and generalist palliative care professionals they came into contact with. Mr Bradley had never been involved in nursing care prior to his wife's illness and really appreciated the development of his ability to care for his wife that he learnt from the visiting district nurses.

"I mean (district nurse), they've all you know, what they've said I've done along with. They are the people who are dealing with this sort of thing all the time aren't they? And you know you've got to take their advice."

Endings and letting go

One of the unique characteristics of family caregiving in palliative and end of life care settings is the realisation that the person being cared for is dying. The consequence of this is that the ill person and the family caregiver will potentially experience a number of losses prior to the actual death. The expectations that were previously taken for granted may be challenged. Plans and dreams about activities that would be undertaken during retirement, which were clearly no longer going to be possible, were expressed by some of the younger family caregivers. Mrs White, a 49 year old special needs teacher reported missing and being angry about the things that she would no longer be able to do with her husband.

"Cheated. ... Because of all the things that we were going to do. And we can't do. For (husband) more than myself I think. All the places that we looked round and, cheated on all the things the we can't do, or (husband) can't do, both of us really. Er, just go for a walk in the woods."

For family caregivers that shared an enmeshed relationship with the ill person, such a loss of dreams and expectations could threaten their own sense of identity. By placing the ill person's need over their own there is a tendency for the family caregiver to ignore or hide a recognition of their own forthcoming loss. This may have enabled them to continue in the family caregiving role, but also reduced their ability to prepare for the death of their relative. Thus, the desire to fulfil the ill person's wishes was generally complied with even if the family caregiver anticipated difficulties in facilitating this. Mrs Taylor was in her 70's and had been a long term caregiver for her husband prior to his diagnosis with cancer. She had a number of health problems of her own. Despite this she had made him a promise and was determined to fulfil it.

"And er, and I've made him a promise that he will die at home, he won't die up there (hospice)." Mrs Taylor.

For Mrs Vaughan, although her husband was admitted to the hospice shortly before he died due to a deterioration in his condition, she was satisfied that she had done all she could to support him for as long as possible at home.

"I don't have any regrets at all, I did all that I could." Mrs Vaughan

Whilst the family caregivers wanted to prolong the life of the cared for person, and enjoy their company and shared experiences for as long as possible, at the same time they did not wish them to suffer or become distressed by their symptoms. Therefore a tension for the family caregiver arose where they may wish the ill person to live and die all at the same time. This tension can be difficult to live with and creates a feeling of disloyalty towards the ill person. The issue for the family caregiver therefore becomes one of attempting to prolong the life and quality of time spent with the ill person whilst at the same time being constantly prepared for their death and mourning the loss of shared experience and expectations that they may have held. Some of the caregivers adapted to this situation by maintaining a sense of normality by continuing to engage in activities with family and friends as often as possible. For Mrs Gardner sharing a family birthday meal with her son and his child was very special.

"As I say on the Saturday they were here for my birthday so we, we all went out for a meal. ... And er, we had a lovely meal and it was very nice, you know, it was nice to have the little family together. So um, the little boy was very good he sat and had his meal." Mrs Gardner.

How the family caregivers prepared for the death of the ill person was often unclear and unspoken. Sometimes the issues were discussed with the visiting health professional, particularly if they came from a specialist palliative care service. With these professionals, talking about and planning for the eventual death of the ill person was seen as acceptable. Within cancer care openness about these issues is almost expected. However, in other long term conditions discussing the potential death of the ill person is not so common and may be avoided altogether. This clearly has implications for the preparedness of the family caregiver for a potential increase in physical care needs of the ill person and the actual process and additional support that may be required or available to them.

CONCLUSIONS

The question that therefore remains is what is the role of the family caregiver in palliative and end of life care settings and is it different from carers in other settings? It is clear that there are numerous challenges faced by family caregivers caring for someone at the end of life. Many of the activities and difficulties experienced by the family caregivers mirror those of carers in other settings. However, undertaking the role of 'carer', sometimes over unexpectedly protracted time frames, and dealing with the tension of living until the death of the ill person is unique to palliative settings. As a result of the perceived urgency and desire to support the ill person, the needs of the family caregiver themselves can often be overlooked and neglected, by the caregiver, the ill person and visiting health and social care professionals. Failing to identify with the role of carer, despite conducting many activities and often developing expertise in caring, can impact on the family caregiver's interactions with health and social care and access to available sources of support for their own support needs. It is therefore important that health and social care professionals understand the perspective of individual family members who may be involved in caring for someone at the end of life whether or not they identify themselves in a caregiving role. This would potentially reduce any tension between expectations of care to be provided by the family caregiver without clear and agreed discussion and appropriate support if required.

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